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ABSTRACT

This essay examines the ways in which health, as a discipline, has been influenced by feminist scholarship in the field. It explains that feminist scientists in the field have recognized and sought to address gender bias in traditional approaches to health research, including the androcentric bias in defining priorities for medical research, the lack of funding for clinical research on women, failure to recognize the effects of gender, and interactions between gender, ethnicity, and class in research. There is growing evidence to support the assertion that access to health care differs in accordance with gender, race, class, and age, and excessive focus on male research subjects and the definition of some diseases as "male" diseases has led to the underdiagnosis and undertreatment of these diseases in older women. It also notes that the exclusion of women of color and lesbians (and their health care needs) from clinical research has often resulted in inadequate or inappropriate theories and conclusions being drawn from the data. (Contains 110 references.) (MDM)

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HEALTH

Discipline Analysis

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WOMEN ^{in the} CURRICULUM

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Women ⁱⁿ the Curriculum

HEALTH

Discipline Analysis

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**National Center for
Curriculum Transformation
Resources on Women
1997**

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PREFACE

Since the 1970s feminist and multicultural scholarship has been challenging the traditional content, organization, methodologies, and epistemologies of the academic disciplines. By now this scholarship is formidable in both quantity and quality and in its engagement of complex issues. The National Center for Curriculum Transformation Resources on Women is therefore publishing a series of essays that provide brief, succinct overviews of the new scholarship. Outstanding scholars in the disciplines generously agreed to write the essays, which are intended to help faculty who want to revise courses in light of the new information and perspectives. Each essay is accompanied by a bibliography that includes references for further reading, resources for the classroom, and electronic resources.

Elaine Hedges

Series Editor

Health

As a continuous stream of newspaper articles has revealed, women are the forgotten gender in much health research. Initial reports focused attention on basic research using male animal models, the theories and conclusions drawn from which might be problematic when extrapolated to female lower animals or human beings. More recent examinations suggest that clinical health research in humans suffers from some of the same flaws as basic research. The selection and definition of problems for study, the choice of experimental subjects, and conclusions drawn from the data in clinical trials often fail to include women or women's changing needs throughout the life span.

Most researchers in the behavioral, biomedical, and physical sciences are trained in the scientific method and believe in its power. Few, however, are aware of its historical and philosophical roots in logical positivism and objectivity. Although every scientist strives to remain as neutral and value-free as possible, most scientists, feminists, and philosophers of science recognize that no individual can be completely objective. Now "objectivity is defined to mean independence from the value judgments of any particular individual" (Jaggar, 1983, p. 357).

In the past two decades, feminist historians and philosophers of science (Fee, 1981, 1982; Harding, 1986; Haraway, 1978, 1989; Longino, 1990) and feminist scien-

tists (Bleier, 1984, 1986; Fausto-Sterling, 1985; Birke, 1986; Keller, 1983, 1985; and Rosser, 1988) have pointed out the bias and absence of value neutrality in science, particularly biology. By excluding females as experimental subjects, focusing on problems of primary interest to males, utilizing faulty experimental designs, and interpreting data based in language or ideas constricted by patriarchal parameters, scientists have introduced bias or flaws into their experimental results in several areas of biology. These flaws and biases were permitted to become part of the mainstream of scientific thought and were perpetuated in the scientific literature for decades. Because more scientists were men, values held by them as males were not distinguished as biasing; rather they were congruent with the values of all scientists and thus became synonymous with the "objective" view of the world (Keller, 1982, 1985).

Gender-Bias in Traditional Approaches to Clinical Research

Once androcentric bias was discovered, feminist scientists set out to explore the extent to which it had distorted science. They recognized potential distortion on a variety of levels of research and theory: the choice and definition of problems to be studied, exclusion of females as experimental subjects, bias in methodology used to collect and interpret data, and bias in theories and conclusions drawn from the data. They also began to realize that since the practice of modern medicine depends heavily on clinical research, any flaws and ethical problems in this research are likely to result in poorer health care and inequity in the medical treatment of disadvantaged groups.

Androcentric Bias in Defining Priorities for Medical Research

Recent evidence suggests that gender bias may have flawed some medical research. The choice of problems for study in medical research is substantially determined by a national agenda that defines what is worthy of study. As Marxist (Zimmerman, 1980), African-American (McLeod, 1987), and feminist critics (Hubbard, 1983; 1995) of scientific research have pointed out, the scientific research that is undertaken reflects the societal bias towards the powerful, who are overwhelmingly white, middle- to upper-class men in the United States. Obviously, the members of Congress who appropriate the funds for NIH and other federal government agencies are overwhelmingly white, middle- to upper-class men; they are more likely to vote for funds for research they view as beneficial to health needs as defined from their perspective. It may be argued that actual priorities for medical research and allocations of funds are **not** set by members of Congress but by the leaders in medical research who are employees of NIH or other federal government agencies or who are brought in as consultants. Unfortunately the same descriptors—white, middle- to upper-class men—must be used to characterize the individuals in the theoretical and decision-making positions within the medical hierarchy and scientific establishment.

Lack of Funding for Clinical Research on Women

Research on conditions specific to females receives low priority, funding, and prestige, although females make up half of the population and receive more than half of the health care. Given the expense of sophisticated equip-

ment, maintenance of laboratory animals and facilities, and salaries for qualified technicians and researchers, virtually no medical research is undertaken today without federal government or foundation support. Responding to this neglect of women's health issues by the scientific community, in 1991 Congress created the Office of Research on Women's Health to address specific issues in women's health. Also in 1991, NIH launched the Women's Health Initiative, attempting to raise the priority of women's health and provide baseline data on previously understudied causes of death in women (Pinn and LaRosa, 1992). The Women's Health Initiative to date has focused on research regarding cardiovascular diseases, cancers, and osteoporosis. Additional examples that might be targeted for future research include dysmenorrhea, incontinency in older women, and nutrition in postmenopausal women. Effects of exercise level and duration upon alleviation of menstrual discomfort, as well as the length and amount of exposure to video display terminals (VDTs) that have resulted in the "cluster pregnancies" of women giving birth to deformed babies in certain industries also have received low priority and might be targeted for future research.

In contrast, significant amounts of time and money are expended upon clinical research on women's bodies in connection with aspects of reproduction. In this century, up until the 1970s, considerable attention was devoted to the development of contraceptive devices for women rather than for men (Cowan, 1980; Dreifus, 1978). Furthermore, substantial clinical research has resulted in increasing medicalization and control of pregnancy, labor, and childbirth. Feminists have criticized (Ehrenreich & English, 1978; Holmes, 1981; Katz-Rothman, 1989) the conversion of a normal, natural process controlled by women into a clinical, often surgical, procedure controlled by men. More recently, new reproductive technologies, such as amnio-

centesis, chorionic villi sampling, *in vitro* fertilization, and artificial insemination have become heavily emphasized, as means are sought to overcome infertility. Feminists have warned of the extent to which these technologies place pressure upon women to produce the "perfect" child while placing control in the hands of the male medical establishment (Arditti et al., 1984; Corea & Ince, 1987; Corea et al., 1987; Hynes, 1991; Klein, 1989; Rosser, 1994).

Additionally, contraceptive research exclusively on women is problematic. Specifically, this type of research has produced birth control methods that permit men to have sexual pleasure without the risk of impregnating women and without the risk of deleterious pharmacological side effects now experienced by women. These examples suggest that considerable resources and attention are devoted to women's health issues when those issues are directly related to men's interest in controlling production of children.

Failure to Recognize the Effects of Gender

Having a huge preponderance of male leaders setting the priorities for medical research results in definite effects on the choice and definition of problems for research: hypotheses are not formulated to focus on gender as a crucial part of the question being asked. Because many diseases have different frequencies (heart disease, lupus erythematosus), symptoms (gonorrhea), or complications (most sexually-transmitted diseases) in the two sexes, scientists should routinely consider and test for differences or lack of differences based on gender in any hypothesis being tested. For example, the study of how a drug is metabolized should routinely include both males and females.

Five dramatic, widely publicized examples demonstrate that sex differences are *not* routinely considered as part of the question asked. In a longitudinal study of the effects of cholesterol-lowering drugs, gender differences were not tested: the drug was tested on 3,806 men and no women (Hamilton, 1985). The Multiple Risk Factor Intervention Trial (1990) examined mortality from coronary heart disease in 12,866 men only. The Health Professionals Follow-Up Study (Grobbee et al., 1990) explored the association between coffee consumption and heart disease in 45,589 men. The Physician's Health Study (Steering Committee of the Physician's Health Study Group, 1989) found that low-dose aspirin therapy reduced the risk of myocardial infarction in 22,071 men. A study published in September 1992 in the *Journal of the American Medical Association* surveyed the literature from 1960 to 1991 on clinical trials of medications used to treat acute myocardial infarction. Women were included in only 20% of those studies; elderly people (over 75 years of age) were included in only 40% of such studies (Gurwitz, Nananda, & Avorn, 1992).

The scientific community has often failed to include females in animal studies in basic research as well as in clinical research unless the research centered on reproductive control. The reasons for the exclusion (to prevent interference from estrus or menstrual cycles, to avoid the fear of induction of fetal deformities in pregnant subjects, and to take advantage of the higher incidence of some diseases in males) may be financially practical, but such exclusion results in drugs that have not been adequately tested in female subjects before being marketed and in lack of information about the etiology of some diseases in women.

Using the male as the experimental subject not only ignores the fact that females may respond differently to the variable tested; it may, ironically, lead to less accurate

models even in the male. Models that more accurately simulate functioning complex biological systems may be derived from using female, not male, rats as experimental subjects. Scientists such as Joan Hoffman (1982) have questioned the tradition of using male rats or primates as subjects. As Hoffman points out, the rhythmic cycle of hormone secretion as portrayed in the cycling of female rat reproductive hormones appears to be a more accurate model for the secretion of most hormones. With the exception of insulin and the female reproductive hormones, most of the 20-odd human hormones were assumed by endocrinologists to remain at constant levels in both males and females. Thus, the male of the species, whether rodent or primate, was chosen as the experimental subject because of his noncyclicality. However, new techniques of measuring blood hormone levels have demonstrated episodic rather than steady patterns of secretion of virtually all hormones in both males and females.

Some diseases that affect both sexes are defined as male diseases. Heart disease is the best example of a disease that has been so designated, because heart disease occurs more frequently in men at younger ages than women. Therefore, most of the funding for heart disease has been appropriated for research on predisposing factors for the disease (such as cholesterol level, lack of exercise, stress, smoking, and weight) using white, middle-aged, middle-class men.

This "male disease" designation has resulted in very little research being directed towards high-risk groups of women. Heart disease is a leading cause of death in all women, and particularly in older women (Kirschstein, 1985; Healy, 1991; Limacher, 1996) who live an average of eight years longer than men (Boston Women's Health Book Collective, 1992). More women than men die each year from all forms of cardiovascular disease (Limacher,

1996). It also is frequent in poor black women who have had several children (Manley et al., 1985). Virtually no research has explored predisposing factors for these groups who fall outside the disease definition established from an androcentric perspective.

Recent data indicate that the designation of AIDS as a disease of male homosexuals and intravenous (IV) drug users has led researchers and health care practitioners to fail to understand the etiology and diagnosis of HIV/AIDS in women (Norwood, 1988). Currently, women constitute the group in which HIV/AIDS is increasing most rapidly, and women with HIV/AIDS have symptoms that differ from those of men (Mehta and Bentrup, 1996). However, it was not until October 1992 that the Centers for Disease Control (CDC) announced a case definition that includes gynecologic conditions and other symptoms related to HIV/AIDS in women; this case definition was enacted in January 1993. This androcentric bias has had serious consequences: most health care workers are unable to diagnose HIV/AIDS in women until the disease has advanced significantly (Mehta and Bentrup, 1996), leading at one point to the average death after diagnosis of AIDS in a man being 30 months, while in a woman it was 15 weeks.

These types of bias raise ethical issues. Because of the paucity of research on women, health care practitioners today must treat the majority of the population, which is female, based on information gathered from clinical research in which drugs may not have been tested on females, in which the etiology of the disease in women has not been studied, and in which women's experiences have been ignored.

Interaction Between Gender, Ethnicity, and Class in Research

When women are used in experimental studies, often they are not accorded the respect due to any human being. In his attempts to investigate the side effects of nervousness and depression attributable to oral contraceptives, Goldzieher (1971a; 1971b) gave placebos to 76 women who sought treatment at a San Antonio clinic to prevent further pregnancies. None of the women was told that she was participating in research or receiving placebos (Veatch, 1971; Cowan, 1980). The women in Goldzieher's study were primarily poor, multiparous, Mexican Americans. Research that raises similar issues about the ethics of informed consent was carried out on poor Puerto Rican women during the initial phases of testing the effectiveness of the pill as a contraceptive (Zimmerman, 1980). Recent data have revealed that at certain clinics routine testing of pregnant women for HIV positivity was carried out without their informed consent (Marte and Anastos, 1990; Chavkin, Driver, and Forman, 1989). Subsequently, pressure was placed on those women who were HIV positive to abort their fetuses (Selwyn, 1989).

Admittedly, it is difficult to determine whether the treatment of these women stems more from attitudes about gender or ethnicity and class. From the Tuskegee Syphilis Experiment, in which the effects of untreated syphilis were studied in 399 men over a period of forty years (Jones, 1981), it is clear that lower-income, African American men did not receive appropriate treatment or information about the experiment in which they were participating. Some of these problematic studies led to new rules and ethics for treatment of human subjects. Scholars (Dill, 1983; Gary, Campbell, and Serlin, 1996; Ruzek, 1988; Spector, 1996;

Vera, 1996) have begun to explore the extent to which gender, ethnicity, and class become complex, interlocking political variables that may affect access to and quality of health care.

Suggestions for relevant research questions based on the personal experiences of women also have been neglected. In the health care arena, women have often reported (and accepted among themselves) experiences that could not be documented by scientific experiments or were not accepted as valid by the researchers of the day. For example, for decades, dysmenorrhea was attributed by most health care researchers and practitioners to psychological or social factors despite the reports from an overwhelming number of women that these were monthly experiences in their lives. Only after prostaglandins were "discovered" was there widespread acceptance among the male medical establishment that this experience reported by women had a biological component (Kirschstein, 1985). Thus, researchers should make an effort to include qualitative experiences and insights of women in the design and implementation of research on women. Using only traditional scientific methods may result in a failure to obtain sufficient information about the problems being studied. Ironically, this is particularly true of the research on pregnancy, childbirth, menstruation, and menopause because these experiences, which are exclusive to women, have been studied almost entirely by methodologies created by men.

Treatment and Access to Health Care

Mounting evidence reveals that access to health care also differs in accordance with gender as well as race, class, and age. Although a variety of factors contribute to

this situation, it may be that bias in clinical research is reflected in bias in access to treatment. Women with kidney failure are less likely than men (30-50 percent depending upon the study) to receive an organ transplant. In one study only 4 percent of women with an abnormal report from a special heart scan were referred for a cardiac catheterization; 40 percent of men with an abnormal report were referred for the procedure (Steingart et al., 1991). Although some recent studies (Bell, Holmes, Perger, et al., 1993; Wetty, Mittleman, Healy et al., 1994) have failed to repeat this finding, one study found that ten times as many women as men die in the hospital after angioplasty (Kelsey et al., 1993). Women who are poor, Black, and elderly often face insurmountable obstacles with the health care system even when they have been diagnosed with a known killer such as breast cancer. Particular populations of women, such as elderly women, women of color, and lesbians provide examples of how research bias becomes translated into treatment and access difficulties.

Elderly Women

The ageism and sexism which have led to bias in the choice and definition of research problems and in methodological approaches to study those problems become translated into medical practices based on the theories and conclusions drawn from the data. These practices may directly affect the accuracy of diagnosis and immediate application of surgical procedures and technologies which may make a difference between life and death for some elderly women.

Excessive focus on male research subjects and definition of some diseases as "male" diseases has led to the underdiagnosis and undertreatment of these diseases in

elderly women. In a 1991 study in Massachusetts and Maryland, Ayanian and Epstein (1991) demonstrated that women were significantly less likely than men to undergo coronary angioplasty, angiography, or surgery when admitted to the hospital with a diagnosis of myocardial infarction, unstable or stable angina, chronic ischemic heart disease, or chest pain. This significant difference remained even when variables such as race, age, economic status, and other chronic diseases such as diabetes and heart failure were controlled for. A similar study (Steingart et al., 1991) revealed that women had angina before myocardial infarction as frequently as, and with more debilitating effects than, men, yet women are referred for cardiac catheterization only half as often. These and other similar studies led Bernadine Healy, a cardiologist and director of the National Institutes of Health, to characterize the diagnosis of coronary heart disease in women as the Yentl syndrome: "Once a woman showed that she was just like a man, by having coronary artery disease or a myocardial infarction, then she was treated as a man should be" (Healy, 1991, p. 274). Since myocardial infarction is the leading cause of death among women in the United States (Healy, 1991), and since it is equally frequent in older men and women, the failure to recognize and treat it adequately leads to unnecessary deaths in some elderly women. Similar problems in recognition and treatment of alcoholism, nutritional deficiency, and sexual dysfunction in elderly women occur because society or the medical profession perceives these as diseases of men, as incompatible with female social roles, or as incompatible with women of particular races or classes.

Focus on male research subjects and definition of some diseases as "male" diseases has also led to the development of surgical procedures and technologies that are inappropriate for elderly women. Studies revealed that a

much higher percentage of women than men died after coronary bypass surgery (Douglas and Brest, 1989; Golding and Groves, 1976; Kahn, Nessin, Gray, et al., 1990). Certainly the slower response of the medical profession in providing appropriate procedures for women presenting with myocardial infarction (Douglas and Brest, 1989; Murdaugh and O'Rourke, 1988; Greenland et al., 1991) and other heart disease suggests that women undergoing coronary bypass surgery may have more chronic, untreated heart disease than the men who undergo the surgery (Ayanian and Epstein, 1991; Steingart et al., 1991). The relatively more advanced average age of women compared to men (Robinson et al., 1988; Limacher, 1996) undergoing the surgery may also be a factor contributing to their higher death rate, although women's greater longevity may partially attenuate the importance of age. The 1976 study by Golding and Groves revealed that a major factor was surgeons' inexperience in performing the operation on the smaller hearts, with smaller veins, and in the more confined pericardial cavities of women's bodies as compared to men's bodies. Because the research on bypassing blocked coronary arteries was conceived to study a problem of significance for men and undertaken using men as experimental subjects, the techniques and skill of the surgeons were honed for the body of the middle-aged man. A particular irony resulting from this initial bias is that many surgeons are reluctant to try the operation on women now that surgical skill (based on practice) is known to be a contributing factor to the higher death rates in women. The study (Kelsey et al., 1993) demonstrating a death rate from angioplasty ten times higher for women than for men is likely to result in fewer angioplasties performed in women, which may explain subsequent studies (Bell, Holmes, and Perger, 1993; Wetty, Mittleman, and Healy, 1994) failing to uncover an equally high death rate for women from angioplasty because the technique would only be used on

ideal female candidates. Exclusion of women as subjects at earlier stages when techniques are being developed and perfected may preclude the real effectiveness of these treatments for women ever being known.

Similar problems may arise with medications. Not only are most medications tested on men, but the dosages are calibrated using the body weight and metabolism of young and middle-aged men. Little research has examined the effectiveness of various medications in women, particularly the dosages for elderly women, who have different metabolic rates, weights, and hormone levels than younger women. The 1992 study (Gurwitz, Nananda, and Avorn, 1992) published in the *Journal of the American Medical Association* which documented the exclusion of women from 82 percent of medication trials to treat myocardial infarction and the exclusion of the elderly from 60 percent of such trials concluded that their omission meant that the effectiveness of medication was not well studied for those groups most vulnerable to myocardial infarction. Perhaps the ineffectiveness in treating diseases or extreme side effects of some drugs encountered by elderly women may be the result of inappropriate dosage levels rather than improper kind of medication.

A holistic view of the elderly woman, including her social, economic, and living situation, must be considered when translating research into health care practice. Because of increased longevity and marriage patterns whereby women traditionally marry men who are older than they are, many elderly women live alone; substantial numbers of women face social isolation and economic problems. Treatments for disease and promotion of health which fail to take into account these factors that result from gender and age are less likely to be successful for elderly women (Jecker, 1991; Lutz, 1989; Chancy and Massion, 1992).

For example, a male cardiac patient who has a wife to supervise his medications, run errands, help him in dressing, bathing, and going to the bathroom, while also taking care of the house and cooking, can be released from the hospital much earlier than a female cardiac patient who lives alone, although many HMOs fail to take these differences into account. Constrained economic circumstances may preclude her from hiring private nursing care and individuals to help with household chores. Her own relative immobility from osteoporosis or partial deafness may have restricted her to relative social isolation. This restriction coupled with the multiple chronic illnesses suffered by her contemporaries means that none of her friends may be able to assume the task of caretaker or even run an occasional errand for her.

The relatively high death rates of elderly women compared to elderly men after hospitalization, not only for cardiac problems (Low, 1993) but also for hip fractures, may be attributable largely to social factors. Absence of caretakers may result in women trying to cope alone or being institutionalized when they could live at home with help. Either result may lead to earlier death for the elderly woman (Boogaard and Briody, 1985; Conn, Taylor, and Abele, 1991; Sharpe, Clark, and Janz, 1991).

Sexism and ageism have biased the choice of problems for study, experimental approaches, and theories as translated into health care practice to push elderly women to the margins of the national health research agenda. This peripheralization represents more than an academic problem of research bias. It represents a cost—a cost to the American taxpayers for increased institutionalization in nursing homes and hospital care, and a cost to elderly women in terms of increased suffering and death.

Women of Color

Exclusion of women of color and their health care needs from clinical research has often resulted in inadequate or inappropriate theories and conclusions being drawn from the data. Clinicians and health care practitioners often translate this misinformation into practice when treating patients. In some cases, the lack of basic information leads to gross errors in diagnosing diseases, performing surgeries, and prescribing treatments. In other cases, stereotypes or inadequate information about sociocultural practices may result in less than optimal health care.

The absence of research and baseline data on some groups of women of color leaves practitioners without basic anatomical and genetic information necessary for diagnosis and treatment. For example, many health care providers are not aware that genetic disorders such as alpha- and beta-thalassemia, hemoglobin E disease, and glucose-6-phosphate dehydrogenase deficiency, as well as diseases such as hepatitis B and nasopharyngeal and stomach cancer, have a higher prevalence in certain subpopulations of Asian-Americans (Manley et al., 1985). The standard dosage of certain medications is often inappropriate for Asian/Pacific Americans, especially women, because of their smaller body size and weight, and certain surgical procedures may require modification for the same reason (Lin-Fu, 1984; Chinese Hospital Medical Staff, 1982).

The absence of basic information about the cultural definitions of health and disease and commonly used folk remedies may lead practitioners to misdiagnose and mistreat a disease. Recent immigrants, partially because of a lack of insurance and of familiarity with how to deal with the health care system, often rely on folk remedies. Some of those used by Asian immigrants have been reported as

toxic. Specifically, traces of lead, arsenic, and mercury poisoning have been discovered and reported (Centers for Disease Control, 1983, 1984). Ignorance of cultural differences complicated by the use of folk remedies may delay diagnosis of the source of the illness by the practitioner.

Targeting women of color for certain types of research may cause clinicians to hold stereotypical views of women of color and particular diseases that limit accurate diagnosis. For example, numerous research studies have focused on sexually transmitted diseases in prostitutes in general (Centers for Disease Control, 1987; Cohen et al., 1988), and African-American women as prostitutes in particular (Centers for Disease Control, 1988). This may lead practitioners to hold a stereotyped view of African-American women. If an African-American woman goes to a health clinic, obstetrician-gynecologist, or emergency room complaining of stomach pain and/or flu-like symptoms, she is often assumed to have a sexually transmitted disease (Boston Women's Health Book Collective, 1992). Even if the woman swears that she is not sexually active, the practitioner may ignore symptoms suggestive of appendicitis or colitis to run more tests to find out which sexually transmitted disease she has. The opposite side of the stereotype is revealed when the practitioner fails to recognize a textbook case of secondary syphilis, including rash, because the woman presenting the symptoms is white, twenty-two years old, and a senior at a prestigious women's college (Gordon, 1977).

Several studies have also revealed that practitioners recognize and report at higher rates crack-cocaine abuse in African-American women and alcohol abuse in American Indian women compared to white women seeking prenatal care. In many cases these women lose their children after they are born or must serve jail time for detoxification. The American Civil Liberties Union reported that in forty-

seven out of fifty-three cases brought against women for drug use during pregnancy in which the race of the woman was identifiable, 80 percent were brought against women of color (Pattrow, 1990, p.2). Other studies have revealed that white middle-class women who use crack cocaine or alcohol during pregnancy are rarely reported and seldom risk losing their children. In March 1987, the state of Florida enacted legislation requiring that women known to have used drugs or alcohol during pregnancy be reported to health authorities. A study (Chasnoff, Landress, and Barrett, 1990) of the results of this mandated reporting revealed that although drug use by both private clients (13.1 percent) and public clients (16.3 percent) and white women (15.4 percent) and Black women (14.1 percent) was similar, Black women were almost ten times more likely to be tested and reported for drug use than white women; poor women using public health care facilities were more likely to be reported than affluent women able to afford private care. It is unclear whether the practitioner fails to recognize the abuse because the woman is white and middle-class or whether s/he simply fails to report it. In either case, the link between targeting African-American women for teen pregnancy and crack-cocaine research and American Indian women for fetal alcohol syndrome research and the reinforcement of stereotypical views held by practitioners seems likely.

Stereotyped views combined with research using methods that uncover only biological bases for health problems that in fact have both social and biological roots may lead practitioners to distance themselves from women of color and treat them inhumanely: sterilization of Puerto Rican women without informed consent (Vasquez-Calzada, 1973); forced sterilization of poor Hispanic or African American women as a condition for receiving Medicaid (Rodriguez-Trias, 1980); giving Chicana women placebos

without their knowledge when they sought contraception (Goldzieher et al., 1971a); coercion of HIV-positive African American women to abort the fetuses they are carrying (Selwyn et al., 1989). Each of these practices represents inhumane treatment of patients by health care practitioners.

Undoubtedly these examples of inhumane treatment and countless other less overt coercions experienced by women of color every day at the hands of practitioners in our health care system have a variety of causes. The major causes in fact are probably not due to flaws in clinical research. However, some clinical research proposes only biological solutions for complex biological/social problems. For example, a biological solution such as Depo-Provera or Norplant implants (McLean, 1993; Washburn, 1996) will be less effective in addressing teen pregnancy in Black females without accompanying strategies to raise self-esteem, increase education, and deal with underlying family dynamics. Stripped of the complex of social, economic, educational, and family dynamics issues that may contribute to teen pregnancy, Norplant implants and Depo-Provera may prevent pregnancy in the short run and lead to the appearance of a solution for teen pregnancy. Without information about family planning, counseling to deal with dysfunctional families, and education and job skills, however, such approaches will not solve the basic problems causing teen pregnancy. These enforced biological solutions place control of the woman's body in the hands of the health care practitioner rather than the woman. This shift in control increases the power of the practitioner and decreases that of the woman. Some practitioners may forget the responsibility that such control entails and use that power for inhumane, coercive purposes. In this sense, flawed clinical research provides an atmosphere in which inhumane treatment seems less heinous.

The combination of racism and sexism has forced women of color to the periphery of the national health care agenda and the priorities for clinical research. Usually they and their health care needs have been ignored in traditional experimental studies. In a few cases, however, women of particular racial/ethnic groups have become the target for certain types of research. The focus of such research typically involves an aspect of reproduction in which a biological solution is sought for a complex medical/social problem, such as crack babies. The bodies of women of color become the battleground over which control of this problem is fought.

The bipolarity surrounding health issues for women of color, in which they are either ignored or targeted, has biased research. The use of the white male as norm or his perspective concerning which health issues are important for women of color has determined the topics chosen for study, methods and approaches, and theories and conclusions drawn from the data.

The traditional research agenda must be changed to focus on the needs of women of color. Their own experiences should inform the determination of which issues are important and serve as the starting point for choosing topics for research. Using women of color and their needs as the central focus opens the door to different approaches to research, which may lead to the emergence of innovative practices to improve and sustain the health of women of color.

Lesbians

Very little research has included separate studies of health care issues for lesbians. The Santa Cruz Women's

Health Collective (O'Donnell, 1977), the Radicalesbians Health Collective (1977), some women's health groups such as the National Women's Health Network, and some studies (Eliason, Donelan, and Randall, 1992; Robertson, 1992) have suggested differences in health and disease processes in lesbians and nonlesbians. For example, it is clear that lesbians have a much lower incidence of certain diseases, such as cervical cancer. Heterosexual intercourse permits the transmission of the herpes, trichomoniasis, chlamydia, and human papilloma virus (HPV) thought to be major causes of cervical cancer. Beginning intercourse at an early age also increases the chances of cervical cancer (Boston Women's Health Book Collective, 1992). Cervical cancer is nonexistent in celibate women and rare in lesbians who have engaged in limited heterosexual intercourse or are not at risk from other factors such as DES exposure and smoking.

In contrast, lesbians may be at higher risk for certain other diseases, such as breast and uterine cancer. Dr. Suzanne Haynes of the National Cancer Institutes estimates that one in three lesbians may develop breast cancer during her lifetime because lesbians are more likely than other women to fall into high-risk categories for the disease (Campbell, 1992). Women who have never had children are at an almost 80 percent greater risk for breast cancer than women who have had children; it may be inferred that lesbians are thus at increased risk because fewer lesbians have children than heterosexual women. Women with a higher body fat content have about a 55 percent greater risk of developing breast cancer; since overweight conditions are more acceptable in the lesbian community, this may present an additional risk factor for lesbians. Because of the need for Pap smears in order to receive birth control pills and a higher incidence of venereal disease, heterosexually active women seek gynecological exams approxi-

mately every eight months. In contrast, lesbian women consult a gynecologist about every twenty-one months. Since gynecological exams include mammograms and breast examinations by physicians, lesbians are subject to these mechanisms for early detection of breast cancer at less frequent intervals than heterosexually active women (Campbell, 1992; Buening, 1992). These health factors, plus evidence that alcohol intake and smoking, factors which increase the risk of breast cancer, have been shown in some studies (Hall, 1992; Buening, 1992; Campbell, 1992) to be higher in lesbians than nonlesbians, led Haynes to theorize the one-in-three rate for breast cancer in lesbians (Campbell, 1992).

Despite these increased risks, few federal research dollars have targeted lesbian health issues as their focus of study. Failure to identify and fund separate studies of lesbian health issues usually results in lesbians' being lumped together with heterosexual women in studies of women's health issues. Combining lesbians and heterosexual women may obscure not only the true incidence but also the cause of the disease. In addition to cervical cancer, the likelihood of most sexually transmitted diseases, including gonorrhea, syphilis, herpes, and chlamydia, being transmitted from males to females during heterosexual activity is dramatically greater than the likelihood of transmission from lesbian contact. Although transmission of such sexually transmitted diseases between lesbians does occur, the incidence is minuscule compared to transmission between male homosexuals, and to male-to-female and female-to-male transmission during heterosexual activities.

When lesbians are lumped together with heterosexual women in studies of incidence and/or cause of sexually transmitted diseases or other gynecological problems from which they are exempt or for which they are at low risk because they do not engage in heterosexual intercourse,

both lesbians and nonlesbians suffer. Defining such studies generally as research on "women's health issues" rather than on "health issues for women engaging in heterosexual sex" leads the general population and some health care workers to think that lesbians are at risk for diseases which they are unlikely to contract, while obscuring the true risk behavior for heterosexual women.

Even when lesbians are defined as homosexual, the norm for their health care issues continues to be the male. Lesbians are usually assumed to be a subset of or very similar to male homosexuals (Anderson, 1981; Corbett, Troiden, and Dodder, 1977; Hudson and Ricketts, 1980). Since male homosexuals are typically distinguished by their deviation from the male heterosexual norm, lesbians again find themselves at a double remove. Lesbians are neither heterosexual nor male; thus their health issues continue to be overlooked or ignored. For example, most current funding for homosexual health care issues is directed toward the study of AIDS. Although lesbians tend politically to support the issue of funding AIDS for society in general, for male homosexuals, among whom the epidemic is rampant (Shilts, 1987), and for heterosexual women, who represent the group in which AIDS is currently increasing most rapidly in the United States (Anastos and Marte, 1989), they receive few direct benefits of this research. Lesbians as a group engage in behaviors that put them at the lowest risk for contracting AIDS, although some lesbians do have AIDS. A recent study (Clay, 1997) revealed that particular subpopulations of lesbians, such as IV-drug users or those who have sex with men who are bisexual or homosexual may be at very high risk for AIDs.

Other health issues significant for the homosexual population may result in lesbians receiving diagnosis and treatment that is less appropriate for them because the male has been chosen as the norm. Alcoholism, a problem

for lesbians as well as male homosexuals, is thought to be underdiagnosed in the lesbian community. Some studies (Fifield, Latham, and Phillips, 1977; McKirnan and Peterson, 1989a, 1989b; Saghir and Robins, 1973) suggest that the drinking patterns of lesbians are more consistent with national norms for male drinkers than for female drinkers (Fifield, Latham, and Phillips, 1977; McKirnan and Peterson, 1989a, 1989b; McNally, 1989; Hall, 1992). Much of the study of alcoholism in homosexual populations has used the gay bar as a source for estimating and diagnosing the incidence of alcoholism (Hall, 1991). Limited research (Luly, 1991; Weathers, 1981) suggests that many lesbians, particularly in some geographic areas, such as the South, and from the upper and middle socioeconomic classes, may not frequent lesbian bars. This does not mean that they are not drinking elsewhere and may not be suffering from alcoholism. Similarly, the twelve-step treatment, the model considered to be most successful for treating alcoholics, was developed by two men using themselves (white, middle- to upper-class heterosexuals) as the norm. Feminists (Tallen, 1990; Muller, 1990; Hall, 1992) have critiqued the confrontational aspects of the model as less appropriate for many women who seek to avoid conflict. The self-revelation aspects of the model and involvement of the spouse in Al-Anon or co-dependents' groups are less appropriate for lesbians, who are likely neither to have a spouse nor to reveal much about their personal life in a lesbophobic society (Deevey and Wall, 1992). In some cases, AA is not sensitive to painful prior events such as rape, incest, battering, or other traumatic events for which alcohol or drug use becomes a symptom (Hall, 1992).

The use of the white heterosexual male as the norm for health care issues has resulted in a lack of information about the health and disease processes of lesbians. The information available often comes from inappropriate extrapolation from the female heterosexual or male homo-

sexual population to the lesbian. The main people damaged by this lack of information are lesbians. Being ignored has led them in turn to ignore themselves with regard to some crucial health care issues. Ironically, lesbians' being ignored or subsumed under "women's" or "homosexuals'" health issues also hurts nonlesbians, especially heterosexual women, who then fail to understand the significance of risk behaviors or lifestyle choices for health and disease processes.

Women of color, elderly women, and/or lesbians experience the effects of sexism combined with racism, ageism, and/or homophobia. Not only does each group have needs that distinguish it from the other groups, but each also has different relationships and maintains different distances from the mainstream clinical research. Given the difficulties with androcentrism and the problems with making research on women's health a national priority, it is not surprising that research on the health of these diverse groups of women is virtually nonexistent. Since an individual woman may simultaneously or eventually belong to one or all of these diverse groups, research on the effects of age, race, and sexual orientation, as well as gender, must become an integral part of the research agenda for the health of women. Failure to distinguish and define needed research for each of these groups of women leaves them ignorant of their own health and disease and confounds research on diseases confined primarily to Caucasian, heterosexually active women of reproductive age.

Conclusion

Women's health became national news in the 1970's as a result of efforts of the women's movement, and particularly groups such as the Boston Women's Health Book

Collective who developed and published *Our Bodies, Ourselves* (1992). In 1985 the U.S. Public Health Service surveyed the nation and recommended changes in the national approach to women's health by expanding the definition beyond reproductive health. Shortly thereafter, the General Accounting Office (GAO) reported that the National Institutes of Health expended only 13.5 percent of its budget on women's health issues, and that the majority of studies on issues affecting both men and women had inadequate representation of women as subjects (Sagraves, 1995). In 1990 the GAO criticized the National Institutes of Health for inadequate representation of women and minorities in federally funded studies (Taylor, 1994), and the Congressional Caucus for Women's Issues introduced the Women's Health Equity Act. Bernadine Healy, MD, became the first woman director of the National Institutes of Health. In 1991 Dr. Healy established the Office of Research on Women's Health with Vivian Pinn, MD, as its first director and announced plans for the Women's Health Initiative (Pinn and LaRosa, 1992). Continued work by Congresswomen, women's health activists, and women's health care professionals led to the Congressional ruling that both gender and ethnic diversity must be represented in clinical trials and the mandate for increased funding for breast cancer, including the largest study to date to be carried out under the auspices of the Department of Defense.

Some of the research and teaching techniques from women's studies and ethnic studies may provide insights and may be used as models to make medical research and the medical curriculum more inclusive of all women and men of color. Established in 1991, the Public Health Service's Office on Women's Health oversees and coordinates research, service delivery and educational activities in women's health. In 1993, the Medical College of Pennsylvania received a grant to integrate women's health into

the medical school curriculum. That same year, The American Medical Women's Association (AMWA) presented the first of a multipart "Advanced Curriculum in Women's Health" for practicing physicians (Donaghue, 1996). Simultaneously, individuals from medical schools around the country developed courses and residencies focused on women's health.

In 1994, the first meetings of the National Academy on Women's Health Medical Education (NAWHME) were held. The Academy emerged from a partnership between AMWA and the Medical College of Pennsylvania and Hahnemann University with the mission of infusing women's health education into all phases of the medical education curriculum: undergraduate, graduate and post-graduate (Donaghue, 1996). Its future plans include publications of curriculum. In its resource guide *Women's Health in the Curriculum: A Resource Guide for Faculty*, (Donaghue, 1996) it lists four institutions (three in the US and one in Canada) offering programs in women's health for undergraduate medical education; nine institutions offering fellowships or residencies specializing in women's health; and nine continuing education courses for practicing physicians centered on specific topics in women's health and offered by the American Academy of Family Physicians (AAFP), AMWA, or Harvard Medical School. Models used to integrate women's studies and ethnic studies into traditional curricula suggest that a specialty in women's health might ensure the inclusion of women and women's health in all aspects of medicine.

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Additional Curriculum Resources

Possible Textbooks

- Boston Women's Health Book Collective. (1992). *The new our bodies, ourselves*. New York: Simon and Schuster.
- Carlson, K.J., Eisenstat, S., & Ziporyn, T. (1996). *The Harvard guide to women's health*. Cambridge: Harvard University Press.
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Collections of Syllabi

Donoghue, G.D. (1996). *Women's health in the curriculum: A resource guide for faculty*. Philadelphia, PA: National Academy on Women's Health Medical Evaluation.

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About the Author

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She has edited collections and written approximately 70 journal articles on the theoretical and applied problems of women and science and women's health. Author of the books *Teaching Science and Health from a Feminist Perspective* (1986), *Feminism within the Science and Health Care Professions: Overcoming Resistance* (1988), *Female Friendly Science* (1990) from Pergamon Press, *Feminism and Biology: A Dynamic Interaction* (1992) from Twayne Macmillan, *Women's Health: Missing from U.S. Medicine* (1994) from Indiana University press, and *Teaching the Majority* (1995) and *Re-engineering Female Friendly Science* (1997) from Teachers College Press, she also served as the Latin and North American Co-editor of *Women's Studies International Forum* from 1989-93. During the fall, 1993, she was Visiting Distinguished Professor for the University of Wisconsin System Women in Science Project.

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|---|---|
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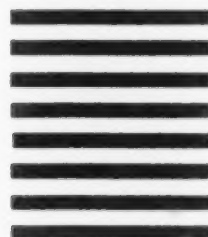
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Publications of the National Center for Curriculum Transformation Resources on Women

WOMEN IN THE CURRICULUM

The following publications consist of directories, manuals, and essays covering the primary information needed by educators to transform the curriculum to incorporate the scholarship on women. The publications have been designed to be brief, user friendly, and cross referenced to each other. They can be purchased as a set or as individual titles. Tables of contents and sample passages are available on the National Center Web page: <http://www.towson.edu/ncctrw/>.

➤ ***Directory of Curriculum Transformation Projects and Activities in the U.S.***

The *Directory* provides brief descriptions of 237 curriculum transformation projects or activities from 1973 to the present. It is intended to help educators review the amount and kinds of work that have been occurring in curriculum transformation on women and encourage them to consult project publications (see also *Catalog of Resources*) and to contact project directors for more information about projects of particular interest and relevance to their needs.

386 pages, 8½ x 11 hardcover, \$30 individuals, \$45 institutions, ISBN 1-885303-07-6

➤ ***Catalog of Curriculum Transformation Resources***

The *Catalog* lists materials developed by curriculum transformation projects and national organizations that are available either free or for sale. These include proposals, reports, bibliographies, workshop descriptions, reading lists, revised syllabi, classroom materials, participant essays, newsletters, and other products of curriculum transformation activities, especially from those projects listed in the *Directory*. These resources provide valuable information, models, and examples for educators leading and participating in curriculum transformation activities.

(Available fall 1997)

➤ ***Introductory Bibliography for Curriculum Transformation***

The *Introductory Bibliography* provides a list of references for beginning curriculum transformation on women, especially for those organizing projects and activities for faculty and teachers. It does not attempt to be comprehensive but rather to simplify the process of selection by offering an "introduction" that will lead you to other sources.

15 pages, 6 x 9 paper, \$7, ISBN 1-885303-32-7

➤ ***Getting Started: Planning Curriculum Transformation***

Planning Curriculum Transformation describes the major stages and components of curriculum transformation projects as they have developed since about 1980. Written by Elaine Hedges, whose long experience in women's studies and curriculum transformation projects informs this synthesis, *Getting Started* is designed to help faculty and administrators initiate, plan, and conduct faculty development and curriculum projects whose purpose is to incorporate the content and perspectives of women's studies and race/ethnic studies scholarship into their courses.

124 pages, 6 x 9 hardcover, \$20 individuals, \$30 institutions, ISBN 1-885303-06-8

➤ ***Internet Resources on Women: Using Electronic Media in Curriculum Transformation***

This manual gives clear, step-by-step instructions on how to use e-mail, find e-mail addresses, and access e-mail discussion lists relevant to curriculum transformation. It explains Telnet, FTP, Gopher, and the World Wide Web, and how to access and use them. It discusses online information about women on e-mail lists and World Wide Web sites. Written by Joan Korenman, who has accumulated much experience through running the Women's Studies e-mail list, this manual is a unique resource for identifying information for curriculum transformation on the Internet. Updates to this manual will be available on the World Wide Web at <http://www.umbc.edu/wmst/updates.html>.

130 pages, 6 x 9 hardcover, \$20 individuals, \$30 institutions, ISBN 1-885303-08-4

➤ ***Funding: Obtaining Money for Curriculum Transformation Projects and Activities***

This manual is intended to assist educators who lack experience in applying for grants but are frequently expected to secure their own funding for projects. The manual provides an overview of the process, basic information and models, and advice from others experienced in fund raising.

150 pages, 6 x 9 hardcover, \$20 individuals, \$30 institutions, ISBN 1-885303-05-x

➤ ***Evaluation: Measuring the Success of Curriculum Transformation***

This manual outlines several designs which could be used when assessing the success of a project. *Evaluation: Measuring the Success of Curriculum Transformation* is written by Beth Vanfossen, whose background in the teaching of research methods as well as practical experience in conducting evaluation research informs the manual's advice. Evaluation is an increasingly important component of curriculum transformation work on which project directors and others often need assistance.

(Available fall 1997)

➤ ***Discipline Analysis Essays***

Under the general editorship of Elaine Hedges, the National Center has requested scholars in selected academic disciplines to write brief essays summarizing the impact of the new scholarship on women on their discipline. These essays identify and explain the issues to be confronted as faculty in these disciplines revise their courses to include the information and perspectives provided by this scholarship. The series is under continuous development, and titles will be added as they become available. See order form for essays currently available.

27 - 60 pages, 6 x 9 paper, \$7 each

➤ ***CUNY Panels: Rethinking the Disciplines***

Panels of scholars in seven disciplines address questions about the impact on their disciplines of recent scholarship on gender, race, ethnicity, and class. The panels were developed under the leadership of Dorothy O. Helly as part of the Seminar on Scholarship and the Curriculum: The Study of Gender, Race, Ethnicity, and Class within The CUNY Academy for the Humanities and Sciences. For this seminar CUNY received the "Progress in Equity" award for 1997 from the American Association of University Women (AAUW).

56 - 85 pages, 6 x 9 paper, \$10 each

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Essays in this *Discipline Analysis* series, edited by Elaine Hedges, summarize the impact on specific disciplines of the new scholarship on women. Written by scholars in the disciplines, these essays identify and explain the issues to be confronted by faculty in individual disciplines as they revise their courses to include women. Each essay provides a valuable bibliography, frequently with a separate listing for internet resources.

Publications available in **WOMEN in the CURRICULUM** series

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